CANCER CARE ONTARIO

Strategic Plan

APPROVED BY THE CCO BOARD OF DIRECTORS
NOVEMBER 25, 1999

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Strategic Plan

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Cancer Care Ontario
Strategic Plan

EXECUTIVE SUMMARY

Cancer Care Ontario's vision is to lessen the growing burden of cancer in Ontario by ensuring that all Ontario residents have timely, equitable access to an integrated system of excellent, coordinated and efficient programs in prevention, early detection, care, education and research.

CCO is one of many partners in Ontario's cancer control system, which is the sum total of all programs and services that prevent and detect cancer, provide care for people affected by cancer, and discover new knowledge and educate the public and professionals about cancer. Collectively, these partners must focus on the needs of people with cancer or at risk of being affected by cancer to improve their health outcomes and their overall satisfaction with the cancer control system.

How will CCO pursue this agenda? In its roles as the Ministry of Health and Long-Term Care's principal adviser on cancer issues, and as an enabler and leader of Ontario's cancer control system, CCO undertook a broad consultation process to develop this strategic plan. Four central themes emerged from the response from stakeholders—CCO must focus on the need for:

- Improved outcomes and satisfaction for patients and the public;
- Collaboration and community involvement;
- Information systems to enable improved outcomes, satisfaction and collaboration;
- Human resource planning, recruitment and retention.

CCO must develop and maintain its ability to **respond sensitively to the continuum of needs of people with cancer or at risk of being affected by cancer, and to communicate clearly and knowledgeably with all stakeholders**. It must learn how to **collaborate more effectively with its existing and prospective partners**, and continue to adapt its relationships and regional organization structures as Ontario's health care system evolves.

To fulfill its role within the overall cancer control system, CCO must develop the information systems and analytical and management capabilities needed to **generate, gather, synthesize, use and disseminate knowledge about cancer**, as well as to **obtain, retain and manage the necessary human, operating and capital resources**. These systems and capabilities must be linked to those of other providers to enable collaborative system-wide planning, with particular attention paid to addressing the serious shortfalls in human resources.

The strategic plan articulates six goals to focus efforts in the quest to lessen the growing burden of cancer in Ontario. CCO has developed the following plan of action to enable, lead and support the cancer control system in pursuit of these goals.

To **reduce the incidence and mortality of cancer in Ontario**, CCO will collaborate with partners in initiatives to prevent cancer and, through screening programs, to find cancer at the

earliest stage possible. CCO will seek funding to launch new screening programs that have been proven to reduce mortality, i.e. colorectal and genetic screening, and will continue to expand the breast, cervical and genetic screening programs. Further research and program development to understand the causes of cancer and to reduce exposures will continue. Information systems are critical to the cancer control system's ability to run screening programs and track cancer trends; therefore, investments will be made in enhancing data collection and recording, as well as in system development. A program in Aboriginal cancer care, designed to reduce the cancer burden on this population, will be implemented.

To **improve the outcomes of individuals with cancer**, CCO will continue its programs in evidence-based care and supportive care. Evidence-based care has the potential to equip both patients and caregivers with the information needed to improve their decision making. Subject to resource availability, investments will be made to expand the use of evidence across the continuum of cancer control and to develop and implement information systems that deliver information when and where it is needed. As for supportive care, the vast majority of services are delivered by organizations other than CCO. Initiatives will therefore focus on collaboration within regions to develop a shared vision, organizational roles and responsibilities for an integrated approach, and to create an agenda for action.

To **improve access of individuals to the cancer system, to expedite movement of patients through the system, and to ensure quality of services available to patients**, the highest priority is to work with partners in identifying, securing and deploying the resources required for patients to receive appropriate and timely care. Key elements will be the training, recruitment and retention of personnel and the development and opening of three new regional cancer centres in the year 2002. Initiatives to support and further integrate caregivers of various disciplines into the cancer system through information sharing and provider networks are detailed in the plan. Resourcing will be pursued for other initiatives including those designed to facilitate access to services for patients through assessment centres, care paths, case managers and a comprehensive managed anticancer drug program.

CCO will provide a forum to enable it and its partners to develop a strategy to **improve the knowledge of the public and professionals as to the causes, indicators and treatments of cancer**. In the meantime, CCO will continue to take a leadership role in improving the knowledge and practice of cancer care among health care professionals. In support of public education, CCO will develop tools to facilitate access to timely information, and will initiate pilot studies on effective education strategies for reaching under-served populations that are known to experience higher cancer morbidity and mortality.

To **advance knowledge about cancer control through research**, CCO must work with its research partners to collate information about cancer research in the province, to identify and support targeted initiatives in key research areas, and to leverage emerging funding opportunities. With the likely establishment of an Institute of Cancer Research under the Canadian Institutes of Health Research, CCO will seek to make the most of opportunities to enter into federal and inter-provincial partnerships as well. This agenda is in addition to CCO's traditional role of providing base support for career researchers in CCO's cancer centres. A major focus for CCO will be to establish a program in translational research, specifically, to support the

training and recruitment of investigators working at the interfaces of fundamental, clinical and population research and to promote and strengthen participation in clinical trials.

Infrastructure must continue to be developed to **ensure the effective planning, organization, management and delivery of cancer control services** across the province. CCO will take steps to ensure continuing evolution of organizational structures and relationships that enable collaborative planning and service delivery, and will work toward linking information systems among providers. It will also work with partners to develop tools for system-wide planning, such as standardized templates for regional operating plans. The acute problem of human resource shortages will receive particular attention, through re-examination of models of care and system-wide human resource plans. The structures and tools for planning must heighten the system's ability to respond promptly to new knowledge about cancer and its treatment; this is especially critical given the potential revolution in cancer care that will come with the sequencing of the human genome, and the identification of genes that determine risk for specific cancers and response to different treatments.

In summary, by focusing on improving outcomes and satisfaction for patients and the public, collaborating with partners, implementing information systems, and planning for and retaining adequate human resources:

- Ontarians can have quicker and easier access than they do now to high-quality cancer prevention, diagnosis and treatment.
- Both patients and care providers can make more informed decisions about preventing or treating cancer.
- Ontario's cancer control system will deliver the best outcomes possible for the resources given to it through provincial and other public funding.

A summary of this strategic plan is provided in the chart that follows.

Strategic Plan Summary Chart

Taking action to strengthen CCO's competencies ...

Respond sensitively to needs of people with, or at risk of being affected by, cancer	Collaborate with partners	Generate, use and disseminate knowledge about cancer	Obtain, retain and manage resources
Enhance decision-making roles of community representatives Develop structures to address ethical issues in decision-making Expand communication skills training for providers Develop strategy for two-way communication	Evolve CCO's internal culture and practices Monitor and adapt to changing roles in the health care system Continue to identify those partners who are essential to realizing the strategic goals Facilitate the ongoing evolution of CCO regional councils and region-specific organizational structures Recognize and support the role of family physicians and community surgeons in the management of cancer care	Safeguard privacy and the confidentiality of personal information Define and implement standard data sets Source and implement clinical information systems Develop data warehouse technology Strengthen capacity for data analysis and evaluation Build the capacity for electronic publishing Promote learning, improvement and rapid response to new knowledge	Enhance CCO's ability to analyze data, forecast and plan for resource needs, with special attention to human resource planning Build the capacity to develop sound 3-year operating plans Strengthen management capabilities Secure appropriate levels of and mechanisms for funding

. . . in order to . . .

... continue working with partners in reducing the burden of cancer in Ontario

Reduce incidence and mortality	**Improve outcomes**	**Improve access and expedite movement of patients**	**Improve knowledge of the public and professionals**	**Advance knowledge through research**	**Ensure effective planning, management and delivery**
Through research in: - Causation - Behaviour - Genetics Through enhanced data capture to monitor cancer cases and causes Through collaborative prevention programs focused on: - tobacco use - diet - other risk factors including occupational exposure Through early detection programs: - Expand breast and cervical screening - Implement genetic and colorectal screening Through a targeted program of prevention & early detection for Aboriginals	Through use of evidence: - Expand use in all areas of cancer control - Develop systems and tools for effective dissemination - Ensure quality & rapid response to new evidence - Evaluate impact on patient outcomes Through supportive care within each region of Ontario: - Harmonize vision among the many providers - Articulate roles & responsibilities - Select initiatives to develop and implement - Improve access to information about services - Attend to palliative care	Through adequate resources for timely care: - Ensure resources across the entire system - Open new cancer centres - Introduce expanded anti-cancer drug program - Ensure supportive care services Through improved navigation: - Develop care paths - Ensure case managers are available for patients in need - Develop and implement assessment centres Through further integration of community caregivers, particularly surgeons and family physicians Through assurance of quality care	Through a collaborative strategy to ensure information needs are met through appropriate communications methods and from credible, accurate sources Through leadership in improving knowledge and influencing practice behaviour of physicians and other health care professionals Through tools to facilitate access to information by the public and patients Through pilot studies on effective education strategies for marginalized populations Through a resource guide to Ontario's cancer system	Through identification of new research opportunities: - Collate information on cancer research across province - Establish central and interlinked research sites on the Internet Through stronger bridges between laboratory/clinic/population: - Establish program to support training in translational research - Promote & strengthen participation in clinical trials Through funding for research: - Identify new funding partners at the provincial and federal levels - Explore partnerships and consortia	Through relationships: - Extend comprehensive cancer centre partnerships Through data: - Information linkages among regional cancer centres, host hospitals and community oncology centres Through planning tools: - Develop templates for regional plans - Implement human resource planning programs Through collaborative search for solutions: - Establish a Cost Information Network to guide system realignment - Promote oncology careers and training - Advocate for suitable funding mechanisms

1 CONTEXT FOR THE STRATEGIC PLAN

1.1 CCO: Mandate and scope

Each year, more than 45,000 Ontarians are diagnosed with cancer, and 23,000 Ontarians die from this disease. The number of people living with cancer continues to increase, not only as a result of aging of the population, but also because people with cancer are living longer.

Cancer Care Ontario (CCO) is a provincial agency with the mandate to integrate and coordinate the province's cancer control services, and to be the Ministry of Health and Long-Term Care's principal adviser on cancer issues. The vision for the agency is to reduce the growing burden of cancer in Ontario by ensuring that all Ontario residents have timely, equitable access to an integrated system of excellent, coordinated and efficient programs in prevention, early detection, care, education and research.

Services that support cancer control in Ontario are delivered by a large number of organizations. These include:

- The Pediatric Oncology Group of Ontario (POGO), which exists to meet the current and emerging needs of the childhood cancer community of Ontario, through collaboration, advocacy, leadership, education and evaluation;
- Publicly funded health care institutions such as hospitals, community care access centres, district health councils, diagnostic laboratories and public health agencies;
- Volunteer organizations such as the Canadian Cancer Society, Willow and numerous peer support organizations;
- Not-for-profit organizations such as community nursing organizations, hospices, and labour unions;
- Information providers such as the Cancer Information Service;
- Individual providers such as family practitioners and general surgeons.

While CCO accounts for roughly 10% of all expenditures on cancer control service delivery, its mandate compels CCO to provide leadership and/or support and/or encouragement for the broad range of services delivered by these many other organizations. This work is conducted through eight Cancer Care Ontario Regional (CCOR) divisions, each containing a regional cancer centre, as well as through a number of provincial programs such as the New Drug Funding Program, the Ontario Breast Screening Program, the Ontario Cancer Genetics Network and the Ontario Cancer Registry.

1.2 Current state

Since its evolution from the Ontario Cancer Treatment and Research Foundation (OCTRF) in April 1997, with an expanded mandate from government and a new name, Cancer Care Ontario has made fundamental changes in how it operates within the cancer control system. *(A more detailed review of CCO's external environment and organizational characteristics is provided in the appendix.)*

In this time period the cancer control system has had to adapt to reform of the health care system, such as restructuring of hospitals and district health councils. Meanwhile, as are almost all facets of health care, the cancer system is struggling with shortages of the trained professionals needed to deliver required services, and with funding that lags behind the pace of growth in the number of newly diagnosed cases of cancer each year. The federal government's plan to create the Canadian Institutes for Health Research should have a positive influence on the quantity and quality of research; at the same time, research developments continue to prompt fiscal pressures as the costs of new drugs and technologies tend to be higher than those they replace. With the explosion of information available on health and health care, public expectations have continued to rise in terms of choice and access to new treatments, and for more accountability from institutions.

Since April 1997, CCO has put into place the basic structures for the operations of eight regional organizations. Cancer Care Ontario Regional (CCOR) councils, comprised of representatives from CCO and its many partner organizations within each region, have been launched and have begun the process of data sharing and problem resolution. While CCOR councils are well-positioned to play their primary role in the planning and coordination of the cancer system, building trust among CCO and all its partners remains a challenge. The management style and skills needed to shift from controlling resources within a regional cancer centre (as was the case under The Ontario Cancer Treatment and Research Foundation) to building partnerships across a region are still under development.

1.3 Strategic plan review

CCO's first strategic plan, approved by its board of directors in October 1997, set out strategic goals to March 2000. To continue the plan into the future, CCO drafted an initial plan based on input received from board members, guests from a number of organizations involved in the cancer control system, and senior staff who attended a strategic planning retreat. The *Strategic Plan Consultation Document* was then distributed to stakeholders through the CCORs, provincial associations and the Internet. Meetings were held with CCOR councils, hospital representatives, the President's Advisory Council and the board of directors of the Canadian Cancer Society, Ontario Division. In addition, more than 50 written submissions were received.

The quality and strength of this strategic plan has grown from the ideas and comments put forward in response to the *Strategic Plan Consultation Document* by these many stakeholders in Ontario's cancer control system.

2 Strategic Plan Direction

2.1 Vision

The vision guiding the first strategic plan continues to provide an authoritative and compelling direction for CCO into the future. It is as follows:

To lessen the growing burden of cancer in Ontario by ensuring that all Ontario residents have timely, equitable access to an integrated system of excellent, coordinated and efficient programs in prevention, early detection, care, education and research.

2.2 Values

The following statement of values is endorsed once again:

Cancer Care Ontario has a primary responsibility to cancer patients and those at risk of being affected by cancer, and an obligation to deliver services in a fashion that recognizes the unique needs of Ontario's various communities and regions.

2.3 Goals

The original five high-level strategic goals are also accepted as originally stated with two modifications. Research has been added as an explicit goal, and the order of the goals has been changed to put patients and the public first and address system needs as a consequence of patient and public needs. Therefore the statement of goals for the current strategic plan is as follows:

1. To reduce the incidence and mortality of cancer in Ontario;
2. To improve the outcomes of individuals with cancer;
3. To improve access of individuals to the cancer system, to expedite movement of patients through the system, and to ensure quality of services available to patients;
4. To improve the knowledge of the public and professionals as to the causes, indicators and treatments of cancer;
5. To advance knowledge about cancer control through research;
6. To ensure the effective planning, organization, management and delivery of cancer control services.

2.4 Four central themes

This strategic plan is built around four compelling themes that emerged from the feedback received from stakeholders. The need:

- To focus on improving outcomes and satisfaction for patients and the public;
- For collaboration and community involvement;
- For information systems to enable these objectives to be achieved;
- For human resource planning, recruitment and retention.

3 BUILDING THE ESSENTIAL CORE COMPETENCIES: INITIATIVES REQUIRED

CCO's effectiveness in enabling, leading and supporting Ontario's cancer control system is related directly to the organization's ability to develop and sustain certain key competencies. Echoing the four central themes that emerged from stakeholder consultation, CCO must have the capacity to:

- Respond sensitively to the continuum of needs of people with cancer or at risk of being affected by cancer, and to communicate clearly and knowledgeably to all stakeholders;
- Collaborate with existing and prospective partners;
- Generate, gather, synthesize, use and disseminate knowledge about cancer;
- Obtain, retain and manage appropriate resources (human, operating and capital).

CCO must undertake a number of specific initiatives within its own organization to develop these competencies and to evolve its organizational culture in a manner that supports and sustains them.

3.1 Capacity to respond sensitively to the continuum of needs of people with cancer or at risk of being affected by cancer, and to communicate clearly and knowledgeably with all stakeholders

The needs of those who are currently, or are at risk of being, affected by cancer must be at the centre of all that Cancer Care Ontario does. The core element required to identify and meet needs is person-to-person communication: the ability to listen, hear and respond at both the levels of making decisions about systems and programs, and within the individual encounter. As CCO takes measures to lessen the growing burden of cancer in Ontario as a whole, it must also ensure that each person who comes into contact with the cancer control system is treated with sensitivity and respect. Furthermore, decision-making processes must be structured to seek out and integrate the perspectives of patients and the public, and to ensure that inherent ethical issues can be addressed rigorously and appropriately.

Initiatives required to enhance CCO's capacity to respond sensitively to the continuum of needs of people with cancer or at risk of being affected by cancer, and to communicate clearly and knowledgeably with all stakeholders:

3.1.1 Continue to support and enhance the involvement of people touched by cancer in the decision-making structures of CCO

CCO has had a policy on community representation in place since 1994. Under this policy, the term "community representative" encompasses individuals who may be cancer patients, family members of cancer patients or advocates for cancer patients, and excludes CCO employees and their immediate family members and health professionals. While community representatives have been appointed to all CCO regional councils and provincial committees, much work remains in assisting the representatives, councils and committees to reach the full potential benefits of community involvement in decision making.

3.1.2 Develop structures to ensure that ethical issues in cancer control are addressed appropriately

The number of controversial ethical issues arising within the cancer control system is increasing. In times of scarce resources, questions around how resources are allocated among various programs and how waiting lists are managed are particularly problematic, and raise many

questions about the underlying values used to make decisions. In order to enable ethical issues to be addressed more rigorously and appropriately for people with cancer or at risk of being affected by cancer, CCO will establish an Ontario Cancer Ethics Program.

3.1.3 Continue to promote participation of front-line providers in communication skills workshops

For several years, CCO staff have been encouraged to attend workshops in improving patient – provider communications. The program has recently been expanded and invitations are beginning to be extended to regional partners. Participation in the program must continue to be supported and reinforced.

3.1.4 Develop a long-term strategy and mechanisms for two-way communication

The consultation process undertaken to develop this strategic plan is an example of CCO's intent to conduct its work in an open, consultative and collaborative fashion. A strategy and mechanisms are needed to expand and improve on CCO's capacity for two-way communication.

3.1.5 Strengthen CCO's efforts in media, public and government relations

To ensure continued public and government understanding of and support for measures to control cancer, resources must be allocated and collaborative mechanisms developed to carry out communications activities with government and the media.

3.2 Capacity to collaborate with existing and prospective partners

While CCO's vision and strategic goals encompass the entire cancer control system in Ontario, it directly manages only about 10% of this system. This fact was recognized when CCO was created, and therefore CCO regional (CCOR) councils and networks were created almost immediately thereafter to provide a structure that would enable collaboration. Collaborative groupings have also come together to build and then implement new program proposals, such as in cervical and colorectal screening.

While CCOR structures are in place and are a key organizational element for CCO, much more work is needed to develop a truly collaborative system. Given the ongoing evolution of and changing roles within Ontario's health care system, the role of CCORs and their composition will need to continue to evolve as well.

Central to the development of a collaborative system, CCO needs to evolve to enable a strong foundation of trust among individuals and organizations. This trust will be earned by CCO only if it continues to involve, and focus on the best interests of, patients and the public.

Initiatives required to enhance CCO's capacity to collaborate with existing and prospective partners:

3.2.1 Evolve CCO's culture and practices in a fashion that is consistent with cooperation, collaboration, and as appropriate, leadership

The culture of CCO must evolve quickly to one in which all providers, including those who are not employed by CCO, are viewed and treated as partners in a common enterprise aimed at reducing the burden of cancer in the Province of Ontario. While CCO must work to earn its leadership credentials, the organization must also learn to distinguish when it must lead and when it should be an enabler to enhance the leadership of other individuals and organizations. The organization must also ensure that it brings value to its relationship with its partners, in order to keep the partnerships alive and productive. To avoid frustration and unnecessary duplication, CCO must take care to develop roles that are complementary to, and supportive of, other organizations.

3.2.2 Monitor and adapt to changing roles in the health care system

Given continuing reforms within Ontario's health care system, CCO must monitor emerging trends and adapt to changing partners and relationships. One important change appears to be the evolution of the role of Ministry of Health and Long-Term Care regions with regional directors, which presents many opportunities (and perhaps some challenges) to the role and functioning of CCORs.

3.2.3 Continue to identify those partners who are essential to realizing the strategic goals

There are existing partners, potential partners, and other individuals and organizations whose roles may evolve so that they become partners in the future. CCO must identify and cultivate relationships with all appropriate partners within the cancer control system, in the broader health care and community sectors, as well as in the private sector.

3.2.4 Facilitate the ongoing evolution of CCO regional councils and region-specific organizational structures that link communities, networks, providers and CCOR councils

Given the growing experience of CCOR councils and the continuing evolution of the health care sector, the mandate, composition and functioning of these councils is due for review, and should continue to be reviewed on a regular basis (likely every 2-3 years). Region-specific organizational structures are under development but need to be extended and strengthened so as to give all cancer providers an opportunity to be at the table and contribute to the work of the nodes, networks and regional councils. To leverage learning among the eight CCO regions, processes must be put in place to enable sharing of best practices and innovations.

3.2.5 Recognize and support the essential role of family physicians and community surgeons in cancer care

While there are many existing and potential partners CCO must recognize and support, the fact that family physicians and community surgeons provide significant cancer care to patients, yet

are challenging to reach because the vast majority work in solo or small group practices, requires a unique initiative in the pursuit of collaborative relationships.

To begin to develop care paths, guidelines and programs that include important roles for the family physician, CCO has taken the step of appointing a provincial coordinator of the Family Physician Initiative. It also has developed a Primary Care Oncology Group as part of the Program in Evidence-based Care. The challenges will be to raise awareness among family physicians of the tools and systems available to them and to raise awareness within the cancer control system of the need to support the family physician. The key interventions will involve improved communications and information systems that can be updated regularly, and work with the Ministry of Health and Long-Term Care to remove barriers that may impede family physicians' ability to fulfill their potential in cancer control. (See also sections 4.1.1 and 4.3.5.)

In a similar manner, the Surgical Oncology Network has been formed to achieve a similar goal in the surgical community. (See also section 4.3.6.)

3.3 Capacity to generate, gather, synthesize, use and disseminate knowledge about cancer

The control of cancer is a complex and resource-intensive endeavour. By its very definition, it requires a strong capacity to generate, gather, synthesize, use and disseminate knowledge. Furthermore the critical need for collaboration among CCO and its partners, as described in the previous section, requires a foundation of trust which in turn demands credibility. This credibility is built upon shared intentions (i.e. putting the best interests of patients and the public foremost in the drive to control cancer) and the creation and sharing of knowledge.

To reduce the burden of cancer in Ontario, CCO is obliged to maximize its capacity to generate, gather, synthesize, use and disseminate knowledge with and among its stakeholders. The initiatives required to do so are highly resource-intensive; funding for these investments will be pursued vigorously, and implementation will proceed as funding is secured.

Initiatives required to enhance CCO's capacity to generate, gather, synthesize, use and disseminate knowledge about cancer:

3.3.1 Safeguard privacy and the confidentiality of personal information

The public in general is very concerned about protection of personal information. There is a fine balance between information that is collected to further the public good and the well being of individuals, and the potential to violate privacy, which is at the centre of current debate as both the federal and provincial governments attempt to proceed with legislation affecting personal health information. As CCO moves forward on the following initiatives, it must continue to ensure that appropriate safeguards are in place.

3.3.2 Define and implement standard data sets

To enable the collection and use of data on cancer control, minimum clinical and management data sets and standardized data definitions are required. As a first step, some level of standardization is required across CCO's programs and centres, and ultimately, greater consistency in data captured across the cancer control system must be pursued (see section 4.6.2.) The data sets must capture both quantitative and qualitative aspects of service need and delivery. In particular, a rigorous and consistent approach toward capturing cancer stage information must be developed and piloted.

3.3.3 Source and implement clinical information systems

Clinical information systems offer the opportunity for diagnostic and treatment information to be collected appropriately and efficiently. For clinicians, these systems can facilitate access and use of clinical practice guidelines and feedback on practice patterns, resulting in enhanced quality and consistency of care. There is a need to identify or develop suitable oncology specific modules to link with the broader clinical information systems now being implemented in most hospitals.

3.3.4 Develop data warehouse technology

Since the data required to understand cancer and manage aspects of the cancer control system reside in many different organizations and formats, data warehouse technology is required to enable these data to be captured, related, analyzed and transformed into new knowledge.

3.3.5 Strengthen capacity for data analysis and evaluation

Data have little value until they are analyzed and synthesized into useful information and translated into knowledge. CCO's mandate requires an enhanced capacity for and focus on data analysis and evaluation. Such functions might be incorporated into a planning unit at provincial office and will require committed management resources at the regional level.

3.3.6 Build the capacity for electronic publishing

The effective dissemination of knowledge requires a number of strategies, which are described in section 4.4. In order to succeed in these strategies, CCO will need to develop its own competencies in sourcing and evaluating material for publication, then transforming and distributing the material in a manner that is understandable and accessible to the relevant audiences.

3.3.7 Promote learning, improvement and rapid response to new knowledge

The extent to which these initiatives will strengthen CCO's capacity to generate, gather, synthesize, use and disseminate knowledge is dependent upon the extent to which the culture of the organization values and pursues learning, improvement and rapid response to new knowledge. The characteristics of this type of culture are consistent with those required of a

collaborative culture (see section 3.2.1) that values two-way (and multi-way) communication with patients, the public and partners (see section 3.1.4). Given the explosion of new knowledge e.g. the potential for gene testing to dramatically alter the way in which cancer prevention and care is delivered, it is critical that CCO and the cancer control system be able to respond rapidly to new knowledge.

A program of specific actions will be developed and introduced to shape and reinforce a culture that supports and nurtures these core competencies.

3.4 Capacity to obtain, retain and manage appropriate resources (human, operating, capital)

None of CCO's strategic goals can be achieved in the absence of sufficient human resources, facilities, equipment and supplies for the cancer control system. The organization requires management systems capable of effective planning, development, deployment and retention of resources. The initiatives described below are needed to develop CCO's overall *capacity* to obtain, retain and manage resources for the cancer control system. Initiatives needed to pursue the actual goals of improving access to the cancer system and ensuring effective planning and delivery of cancer control services can be found in sections 4.3 and 4.6.

Initiatives required to enhance CCO's capacity to obtain, retain and manage appropriate resources:

3.4.1 Enhance CCO's ability to analyze data, forecast and plan for resource needs

Section 3.3 spoke to the generic need for CCO to develop its capacity for data collection and analysis. CCO's ability to forecast service needs and resource requirement must also be developed to ensure resources are in place to meet changing needs. Incident data from the Ontario Cancer Registry must be reviewed at regular intervals and considered together with changing demographics, the impact of new treatment approaches, screening and preventive approaches. More consistent capture of data on type and stage of cancer will enhance the accuracy of forecasts and plans. CCO also requires the capacity to model care delivery, to link it to resource and funding needs, and to adapt the models as care delivery evolves. Establishment of a planning unit (see section 3.3.5) will further CCO's competency in this regard.

3.4.2 Build the capacity to develop sound three-year operating plans that integrate planning for human resources, facilities, pharmaceuticals, information technology and capital equipment

One of CCO's goals is to ensure effective planning of the cancer control services across the province; achieving this goal requires solid and consistent strength in CCO's ability to develop comprehensive plans for the services it delivers. To avoid crises in the complex and highly specialized cancer control system, planning horizons need to be extended immediately to three years, and ultimately to five years.

3.4.3 Strengthen management capabilities

Retaining and deploying resources as effectively as possible requires strong management skills. In particular, quality of working life and labour relations are significantly affected by the quality of the working relationship between employees and their direct managers. Programs in management development (including coaching and mentoring) and succession planning are required.

3.4.4 Secure appropriate levels of and mechanisms for funding

Ontario's cancer control system requires the assurance of funding and the flexibility to respond to increasing patient numbers and patient needs, and advancing knowledge. As CCO leads the development of more effective plans for cancer control services, it will also explore the feasibility of advocating the extension of per case funding to programs in addition to radiation therapy. As CCO strengthens its relationship with the Ministry of Health and Long-Term Care, it may have the opportunity to advocate for more timely replies to operating plans. By developing partnerships with the private sector or through consortia, CCO also has the opportunity to obtain non-MOHLTC funds for research programs and information systems.

4 PURSUING THE GOALS: INITIATIVES REQUIRED

The previous section (section 3) of this strategic plan described what Cancer Care Ontario must do to develop its internal competencies in order to enable, support, and as appropriate, lead the cancer control system in pursuit of the goals that are articulated in this section (section 4). The initiatives described herein require collaboration among and contributions from many stakeholders. CCO's role in pursuing each initiative is articulated, and it is hoped that partners will find themselves engaged by their intent and be inspired to collaborate in fulfilling them.

4.1 To reduce the incidence and mortality of cancer in Ontario

The major opportunities to reduce the incidence and mortality from cancer, based on existing knowledge, lie within the field of preventive oncology. These opportunities include:

- Prevention, i.e., the elimination or avoidance of the causes of cancer. This strategy aims to reduce both cancer incidence and mortality.
- Screening, i.e., the early detection of cancer at a presymptomatic stage through an organized program. The principal objective of screening is to reduce cancer mortality. Some cancer screening programs also have the potential to detect precancerous lesions and, therefore, actually reduce cancer incidence as well.

Initiatives required to reduce the incidence and mortality of cancer in Ontario include:

4.1.1 Facilitate participation of and contribution by those who are well positioned to provide prevention and/or screening services

As articulated in section 3.2, collaboration is critical to achieving the vision of reducing the burden of cancer in Ontario. The Ontario Network for Cancer Prevention, a linkage group of key stakeholders, provides a vital enabling mechanism. Its membership includes senior staff from the division, CCOR prevention and screening coordinators, representatives from the Ontario College of Family Physicians and the Canadian Cancer Society, Ontario Division and other key stakeholders. ONCP will engage key collaborators, including health care providers, other prevention-oriented agencies, consumers and the private sector. ONCP will establish provincial priorities and identify the roles and responsibilities of the partners. CCOR prevention and screening networks will be the key bodies for regional planning and coordination.

Primary care providers, particularly family physicians, play a vital role in preventive oncology. Their support is critical to the success of cancer screening. Family doctors are important providers of some cancer screening procedures, such as Pap tests, and the gatekeepers to other screening procedures, such as mammography. They are a key source of health information for patients about primary prevention of cancer.

CCO must actively support the participation of and contribution by those who are well-positioned to provide prevention and/or screening services. This role will include involvement of their representatives in program planning and coordination. (See section 3.2 also.) CCO should develop evidence-based guidelines for preventive oncology interventions, such as counselling about smoking cessation. (See section 4.2.1.) CCO should develop programs in continuing education to support these interventions. CCO should advocate to the Ministry of Health and Long-Term Care that family doctors should be adequately recompensed for their preventive oncology services.

4.1.2 Advocate for change to public policies that affect cancer prevention

CCO must speak out effectively regarding public policies that affect cancer prevention. A prime example is the impact of public policy on teenage smoking. There is substantial evidence that higher prices are an effective deterrent to tobacco addiction among adolescents, and so public policy that supports higher tobacco taxes is effective preventive oncology.

4.1.3 Provide comprehensive surveillance of cancer cases and the determinants and causes of cancer

Cancer surveillance is an essential element of cancer control. It is important to obtain detailed information about all cancer cases and a broader understanding of the distribution of the causes of cancer. This knowledge will be necessary for CCO to fulfill its mandate in cancer prevention, screening and treatment.

The Surveillance Unit of the Division of Preventive Oncology operates the Ontario Cancer Registry and has lead responsibility for comprehensive surveillance. Key initiatives to enhance cancer surveillance will include:

4.1.3.1 Establish pilot projects to enhance the Ontario Cancer Registry, including capture of cancer stage data

The Ontario Cancer Registry has provided an excellent service of documenting incident cancer cases and cancer deaths for more than 30 years. The registry provides efficient record linkage of data from a variety of sources. The registry provides Ontario with excellent information at a fraction of the cost of more elaborate cancer registries in the United States.

The registry does, however, have important limitations. Most prominent is the inability to document cancer stage or describe treatment. Information of this kind will be essential for CCO to coordinate cancer care and to monitor and compare outcomes across the system. Better cancer surveillance is a core element of knowledge management for CCO.

The registry proposes to launch a pilot project to test the feasibility of capturing enhanced information about cancer cases, including stage. The cost of this project is estimated at $450,000 over two years. If successful, it would establish a prototype for the province, with a probable additional cost of $3-million to $5-million per year.

Another important longer term initiative will be the development of the capacity to obtain the registry data in real time by point of encounter data capture rather than having to obtain data one to two years later.

4.1.3.2 Produce surveillance products that support CCO's priorities in cancer control

Information about cancer surveillance must be presented in surveillance products. These surveillance products can serve a number of audiences and purposes. Surveillance products can be technical documents for professionals and scientists, popular reports for the general public or analyses aimed at policy makers.

CCO has, for example, produced excellent monographs on colorectal cancer and cervical cancer, to support screening initiatives. Surveillance information played a critical role in supporting CCO's funding proposal to the Ministry of Health and Long-Term Care regarding colorectal cancer screening. CCO has also incorporated surveillance information in its annual report card. The Surveillance Unit is discussing with the CCORs the potential for producing an annual report on cancer for each CCOR.

The Surveillance Unit will continue to produce at least two cancer monographs each year. It will produce annual cancer statistics for each CCOR and work with CCOR networks to determine the best means of presenting this information.

Production of well-crafted and accessible surveillance products requires comprehensive and accurate surveillance and an important investment in communications and production values. This latter aspect may cost up to $250,000 per year.

4.1.3.3 Strengthen behavioural risk factor surveillance

Prevention of cancer requires action to reduce the causes and determinants of cancer. Control of lung cancer, for example, requires information about smoking rates and public policies that affect these rates. CCO must partner effectively with other organizations that have a role in surveillance of causes and determinants.

The Surveillance Unit has undertaken a pilot project of behavioural risk factor surveillance in partnership with Health Canada, the Ontario Ministry of Health and Long-Term Care and the Durham Region Health Unit. If successful, this pilot would form the prototype for province-wide risk factor surveillance. This surveillance likely would cost $1-million to $2-million per year.

4.1.4 Support research that addresses critical issues and key opportunities in preventive oncology

4.1.4.1 Establish an active program in behavioural research

A better understanding of human behaviour with reference to preventive interventions is critical to their success. This is equally true for behavioural risk factors and cancer screening programs. In April 1999, the Research Unit brought on its first behavioural science researcher. Over the next few years, the unit will develop an active program in behavioural research for preventive oncology.

4.1.4.2 Expand and enhance research into genetic screening

As more is learned about genes and their relationship to disease, the demand for genetic screening will increase. The Ontario Cancer Genetics Network has grown to become the largest cancer genetics research program of its kind in North America. In addition to research, it provides province-wide testing and counselling for individuals at high risk of breast or colon cancer, and at one centre, for melanoma as well. To date, OCGN has been entirely supported by research funding from CCO and the National Cancer Institute (US). Program funding is needed to continue the testing and counselling program.

4.1.4.3 Continue research into the causes of cancer

Determining the causes of cancer is the single most important task of preventive oncology research. Scientists in the Research Unit are involved in a number of studies examining different lines of enquiry. Strong links with cancer surveillance, particularly with the Ontario Cancer Registry, are an excellent base for etiological research. CCO must continue to support researchers in this field.

4.1.5 Synthesize knowledge about cancer prevention and cancer screening

Cancer prevention policies and programs must be evidence based. The nature of the evidence regarding cancer causation makes this determination more difficult than with clinical interventions. Issues of cancer causation are not, in general, determined by specific clinical trials. Rather, they must rely much more on observational evidence. As a result, the evidence may be ambiguous and contradictory.

The challenge for CCO is to deal intelligently with uncertainty, incorporate the perspectives of a wide range of stakeholders, and determine when the evidence is good enough to support specific prevention programs and policies. Certainly, proof beyond any doubt is not a reasonable standard of evidence. For example, there is good evidence to support programming recommendations to reduce total caloric intake in order to reduce overweight, and thereby reduce cancer risk. However, current evidence may not be strong enough to support recommendations on limiting consumption of particular types of fat. CCO has created the Ontario Collaborative Group on Diet and Cancer to try to achieve scientific consensus on the diet/cancer association and provide advice on reasonable programs and policies. There are similar issues with regard to physical activity, environmental pollution and other cancer risks.

Knowledge synthesis for cancer screening is also important. It must incorporate evidence of the effectiveness of screening as well as ethical, consumer and health systems issues. The report and recommendations of the Ontario Expert Panel on Colorectal Cancer Screening is a model of this type of deliberation

4.1.6 Develop an active and effective program in the primary prevention of cancer

Prevention of cancer is our single best opportunity to improve cancer control in Ontario. CCO must establish a program in cancer prevention that builds on its own organizational strengths and works through partnerships with other organizations. Our challenge is to add value to the efforts of public health agencies, the Canadian Cancer Society, family doctors and others active in this field.

As stated in section 4.1.2, CCO can function as an advocate, in collaboration with its partners, for cancer prevention. CCO can provide evidence-based guidelines for primary care providers and others to support the provision of prevention activities. CCO can establish itself as an expert resource on public policy as it affects the causes of cancer, including policies on issues such as tobacco taxation, smoking bylaws and tobacco industry sponsorship of sporting and cultural events. This expertise can draw on natural links with the Surveillance Unit.

The *Report of the Ontario Task Force on the Primary Prevention of Cancer* (1995) identified a broad range of prevention opportunities. CCO will develop a prevention program based on the priorities established by the task force:

- Tobacco use is responsible for approximately 25% of fatal cancers in Ontario. CCO will be active in tobacco prevention by assisting the Ontario Tobacco Strategy. CCO will assist the Ministry of Health and Long-Term Care with the development and coordination of a

comprehensive tobacco control program in 1999–2000. CCO is a member of the Ontario Campaign for Action on Tobacco and will be forceful advocate for tobacco control.

- Diet, including alcohol, and physical activity account for at least 30% of fatal cancers in our province. CCO has established the Ontario Collaborative Group on Diet and Cancer as a first step in this area.
- Occupational cancer is an important concern. CCO will become involved in preventing occupational cancers, beginning with improved surveillance. CCO will create a collaborative group of stakeholders and experts to make recommendations regarding the most effect means of surveillance of occupational cancer. A variety of surveillance strategies have been proposed, including routine reporting of occupation with incident cancer cases. The utility of these strategies must be assessed and the effective approaches incorporated into our cancer surveillance.
- Environmental carcinogens are a source of concern and controversy. CCO will identify opportunities for evidence-based (see section 4.1.5) interventions in this field.

4.1.7 Implement effective screening programs for early detection of cancer

Early detection of cancer through screening can reduce mortality from breast, cervical and colorectal cancer. CCO is responsible for providing screening programs that are well organized, high quality and reach as many eligible people as possible. Genetic screening is a rapidly developing area of preventive oncology. Some genetic tests have now become established as clinical services. CCO must develop the capacity to provide these services and meet future demands as new tests emerge. CCO also must maintain an active watch on new evidence related to screening for diseases such as prostate cancer. When there is sufficient evidence to warrant new guidelines and new programs, CCO must move expeditiously to provide leadership.

4.1.7.1 Continue to expand Ontario Breast Screening Program

The Ontario Breast Screening Program provides comprehensive breast screening to women 50 years of age and older. OBSP provides its services through eight hub sites, one mobile van and a growing number of affiliate sites. OBSP will continue to expand its number of affiliate sites, to promote access and to ensure quality breast screening. OBSP plans on expanding at a rate of about 20 new sites each year for the next two to three years.

OBSP's target is to screen 70% of eligible women—approximately 350,000 screens per year. OBSP screened 106,000 women in 1998-99. It plans on increasing its screens by approximately 50,000 per year until it reaches its target. This objective will be achieved by increasing the number of affiliate sites and by continued efforts in public education and recruitment of hard-to-reach women. Discussions also are under way about making OBSP screening available to women between 40 and 49 years of age.

Ensuring rapid and accurate assessment of any abnormalities detected is a criterion for an excellent screening program. OBSP will work with health care providers to ensure that comprehensive high-quality assessment is available for all OBSP-screened women. OBSP has an affiliation agreement with one assessment site and plans to expand this aspect of the program over the next few years.

4.1.7.2 To continue to implement the Ontario Cervical Screening Program.

The Ontario Cervical Screening Program is still developmental. Its aim is to build on existing services to provide a comprehensive and coordinated province-wide system of quality cervical screening to which all women will have access. CCO will work with the Ontario Cervical Screening Collaborative Group and other partners in the screening pathway to promote screening among women and their health care providers, to ensure quality of all aspects of the program and to provide a systematic system of recall and follow-up for women.

CCO is in partnership with INSCYTE which owns a cytology information system called CytoBase. CytoBase contains records from more than 50% of the Pap tests performed annually in the province, which are from two major private laboratories. CCO must work with the ministry to remove the legislative barriers preventing the sharing of medical records in order to have a complete registry of women. It is intended that Cytobase will maintain the screening histories of each woman, will enable the recall and follow-up of women, support quality assurance and facilitate program planning, monitoring and evaluation.

CCO will also work with its partners to provide information to women and primary health care providers on cervical cancer and the benefits of screening. The agency will also collaborate with professional organizations to develop and disseminate cervical screening evidence-based guidelines and best practices for health care providers to promote quality and consistency across the province.

CCO must address a number of challenges if it is going to have an organized program in place in the year 2000. The program needs to provide information to women on the database and address confidentiality issues. It must also tackle the difficult problem of increasing cervical screening among the hard to reach populations. Lastly, it must strengthen its capacity and seek enhanced program resources.

4.1.7.3 Implement the Ontario Colorectal Cancer Screening Program

The Ontario Expert Panel on Colorectal Cancer Screening recommended, in April 1999, that CCO implement a comprehensive, organized program to screen for colorectal cancer, based on fecal occult blood testing (FOBT) and follow-up assessment of positives for all Ontarians 50 years of age and older. The CCO board endorsed this recommendation and submitted a funding proposal to the Ministry of Health and Long-Term Care.

CCO must continue to pursue funding for this program and, when funding is obtained, implement this program. Implementation will require active partnerships with family doctors, medical specialists, hospitals and consumers.

4.1.7.4 Establish program support through the regional cancer centres for genetic screening of individuals at high risk for breast and colorectal cancer

The Ontario Cancer Genetics Network has established a province-wide network for genetic testing based on research protocols financially supported by CCO and the NCI (see section

4.1.4.2). This testing is now becoming established as a clinical service. Research funds will sunset and research priorities will move on. CCO must, therefore, establish a funding base to support genetic screening as a clinical service. CCO has submitted a budget request to the Ministry of Health and Long-Term Care to begin this transition. Services currently provided through OCGN will cost approximately $2.5-million per year.

4.1.8 Plan and implement the Aboriginal Cancer Care Program

Aboriginal people living in Ontario have a range of special needs with regard to cancer. These needs include cancer programs that are culturally appropriate, access to cancer treatment and supportive care, and important cancer prevention issues. CCO, in partnership with Aboriginal groups, has obtained funding for the Aboriginal Cancer Care Program. The first phase of the program is in progress, i.e. a manager and two coordinators are being recruited. These staff will be responsible for developing program initiatives under the direction of the Joint CCO-Aboriginal Cancer Care Committee.

4.2 To improve the outcomes of individuals with cancer

While CCO strives to reduce the incidence and mortality of cancer, it must also work to improve the outcomes of those who are living with the disease and those who may die of their disease. Research will lead to new and more effective approaches to diagnosis and treatment (see discussion in section 4.5). Through the evidence discovered by research and translated into practice guidelines, care paths and program design, patients will receive more effective care at all points in their illness. At the same time, the outcomes for and quality of life of individuals living with cancer or dying of their disease will be improved through the development and implementation of supportive care programs.

Evidence-based care refers to an explicit process for being able to find and evaluate the highest quality information (evidence) available, and to apply it in order to achieve the best outcomes for cancer patients within the resources available to the health system. "External evidence" refers to the results of formal research studies about best practices that are usually made available as publications in peer-reviewed clinical scientific journals. Such information originally was considered to be the most important in what has been called "evidence-based practice". Internal evidence refers to information that is generated within a particular health system about how well the system is performing. Internal evidence is available to those within the organization, and is part of what has been called "outcomes research". Internal and external sources of evidence about best practices are complementary, and both are important in Cancer Care Ontario's definition of evidence-based care. To improve outcomes for patients, the evidence-based approach should harness new information from formal research, and be prepared to feed back to clinicians and managers information about current practices so they can be improved.

With respect to internal evidence, the CCO Program in Evidence-based Care has established formal collaborations with the Institute for Clinical Evaluative Sciences to conduct research about oncology practice and patients' outcomes across Ontario's cancer system. The plan is to extend this collaboration to include the Radiation Oncology Research Unit in Kingston. These initiatives will focus on the relationship between actual practice and recommended practice from

clinical practice guidelines, and the effects on patients' outcomes. These initiatives are an important part of the evaluation function that the program brings to CCO.

With respect to external evidence, the CCO Program in Evidence-based Care has completed more than 35 systematic reviews of the published literature, and has approved 29 clinical practice guidelines primarily related to cancer treatment. These guidelines undergo evaluation by the practicing oncology community before they are finalized.

The approach used by the program involves research methods, and the program's objectives are clearly designed to take advantage of published research to improve practice. There is a strong evaluation component to the program's activities, especially as they relate to outcomes research projects, and surveys of practitioners about the quality and relevance of guidelines.

Supportive care is the provision of the necessary services as defined by those living with or affected by cancer to meet their physical, informational, emotional, social, psychological, spiritual and practical needs, during the prediagnostic, diagnostic, treatment and follow-up phases, encompassing issues of survivorship, palliation and bereavement. The delivery of supportive care involves a wide range of individuals and agencies. Aspects of supportive care must be integral to the practice of *all* health care professionals and is demonstrated in actions such as offering the patient and family emotional support and information in the course of their interactions, and referring them to supportive care experts. In addition to the supportive care provided to patients and families by oncologists, nurses, radiation therapists, pharmacists, and so on in the course of diagnosis and treatment, a full supportive care program includes the services provided by individuals such as:

- Professionals who work in private practice in the community or within a private or non-profit institution or organization such as social workers, psychologists, family physicians, palliative care physicians, dieticians, clergy/chaplains, specialty nurses, physiotherapists, occupational therapists, speech therapists, as well as therapists in fields such as art, music and touch.
- Volunteers who offer peer support, drive patients to treatment and give practical and financial support.

For the individual who is living with cancer or who is dying of the disease to experience effective supportive care, the system for delivering that care must be coordinated. The full range of care providers, within both institutional and community settings, must work collaboratively. Regional networks for supportive care have been established, using a community development approach, to foster this collaboration and must continue to evolve. To achieve the strategic goal, each regional network will have to come to grips with the different perceptions held regarding what is meant by supportive care and articulate a common vision within its region that can serve as a touchstone for reviewing progress towards the goal.

Because supportive care applies across the entire continuum of cancer care, from screening and diagnosis to advanced disease and bereavement, regional networks will need to set priorities to focus their programs, yet decide how a network can function to deal with a diffuse array of needs in the longer term. This approach will require the identification of unique regional needs, and the setting of priorities that have regional sensibility. An articulation of needs, roles, and plans for

integration of services will be required. Sharing information about needs and roles will be crucial if integration is to occur with the willing participation of all the players.

Finally, it is unrealistic to expect regions to move on all fronts simultaneously in trying to meet the needs of supportive care. While an integrated system that meets all, or most, needs is an ultimate goal, it seems prudent to plan for early successes. This objective would be achieved best by identifying well-bounded, individual project proposals to deal with the specific issues. Eventually, this approach can expand into a series of related projects once the partners have had the advantage of experiencing how they can fit into a collaborative regional model.

Initiatives required to improve the outcomes of individuals with cancer through evidence-based care:

4.2.1 Expand the use of evidence along the continuum of cancer control, and extend it to the management domain

The capacity of the Evidence-based Care Program must be extended to address the issues from prevention through to screening, diagnosis, treatment, supportive care, follow-up and rehabilitation, and other aspects of patient care (e.g., diagnosis, follow-up, pathology review). Regional collaborations are needed to develop care paths, starting with inventories of care paths and of expertise in care path development, and moving toward the establishment of generic pathways that can be modified for use within different regions. Extending evidence-based principles to the management domain will foster a positive institutional environment and sound management practices.

4.2.2 Ensure effective dissemination strategies so that information about best practices is placed into the hands of those who need the information, and influences behaviour change

4.2.2.1 Develop clinical information systems to monitor and influence practice at the clinical encounter

Clinical information systems have the capacity to track clinical processes of care and patient outcomes, and to aggregate this information across patients. This capacity would enable evidence-based information to be provided at the time when it is needed for decision making, and it would provide feedback to clinicians about their practices close to the clinical encounter.

4.2.2.2 Develop tools for access to electronic information by patients, such as Internet in the clinic

In keeping with our patient-centred focus, CCO should concentrate on how to use current information that is available to patients in a way that enables patients and their families to access the information for decision making, evaluate it and trust that their providers will welcome discussions around such information resources. This initiative will contribute to the patient-mediated interventions mentioned above.

4.2.3 Ensure quality guidelines and care paths and enable rapid response to new evidence

The program must be resourced to engage in high-quality research using the most appropriate and valid evaluation methods, and to be able to keep evidence up to date. Given the rapid pace at which new evidence becomes available, attention should be paid to devising a decision-making structure that is flexible enough to respond in a timely fashion to new information.

4.2.4 Evaluate the effectiveness of guidelines and other evidence-based strategies in influencing the quality of care and patient outcomes

The evidence-based approach adopted by Cancer Care Ontario through the establishment of a specific program area strongly implies a commitment to evaluation as an important component of all its programs, including the evaluation of guidelines themselves. Subject to resource availability, projects will be undertaken to evaluate the extent to which guidelines and other evidence-based strategies have a positive influence on quality of care and patient outcomes.

Initiatives required to improve the outcomes of individuals with cancer through supportive care:

4.2.5 Within each region, harmonize the vision for providing supportive care cancer services

A supportive care template has been developed and supportive care standards have been written. These tools can be used as a basis for discussion by the regional networks to plan appropriate regional goals, objectives and performance expectations for enhancing supportive care delivery in a region. It is critical that each regional supportive care network design and implement strategies that are appropriate for its respective region and will achieve the improved outcomes regarding supportive care. It is also critical that regional networks build on existing relationships and integrate effectively with existing palliative care initiatives (e.g. pain and symptom coordinators, community care access centres, self-help networks, etc.)

4.2.6 Articulate the organizational roles and responsibilities for an integrated approach to supportive care involving community based agencies, informal support groups and the formal health care system

Supportive care is not the prerogative of any one health care discipline or any one agency, organization or group. If the individual who is living with cancer is to experience effective supportive care, the system for delivering that care must be coordinated. It must embrace the full range of care providers, including those in institutional settings and those in community settings. The breadth and scope of supportive care necessitates that a wide range of agencies work together in partnership.

As a patient moves across the spectrum of illness from diagnosis to treatment and rehabilitation, or experiences recurrence or requires palliative care, agencies and organizations will possess different expertise in providing care to that individual. Each agency or organization may have different services to offer. If we are to avoid duplication and fill current gaps in care delivery, and have a

coordinated and comprehensive system, the agencies and organizations need to define their respective roles and responsibilities for care provision. They need to agree upon who delivers what services and negotiate how they will operate together in the best interests of the patient. The agencies and organizations need to work through their supportive care networks to engage in a process of collaborative goal setting for supportive care in their region and cooperative planning for service delivery. The various agencies and organizations need to organize their care delivery models so that patients and families experience continuous supportive care with timely access to appropriate supportive care services whether they are in the hospital or living in their home community. Patients and families require continuity of care throughout their experience with cancer and timely access to palliative care and pain control expertise.

4.2.7 Initiate a plan to promote evidence-based supportive care services in collaboration with others

The evidence base for guiding practice in supportive care is growing quickly. It needs to be readily accessible to practitioners if they are to use it in their daily practice and have the confidence that they are delivering effective interventions. Currently, heavy clinical workloads, lack of easily accessible routes to the literature, difficulty critiquing the literature and the scope of supportive care are serving as barriers for practitioners in utilizing the existing evidence in their daily practice. The availability of evidence-based guidelines for practice would be most useful in overcoming such barriers.

A plan needs to be developed and implemented for promoting the need for and importance of evidence-based supportive care services, and for producing appropriate guidelines for practice. Clearly this plan needs to involve the participation of supportive care practitioners if it is to be successful. The challenges in producing supportive care guidelines include selecting appropriate and relevant topics for guideline development and involving the appropriate range of practitioners for any one topic area.

Although ground-breaking work is under way through the Supportive Cancer Care Research Unit in Hamilton and Thunder Bay, there is lack of research regarding some aspects of supportive care. Research efforts need to be enhanced and links need to be created with academic researchers who work with topics of relevance to supportive care. Fundamental to enhancing the research effort in supportive care is increased funding for this research and protected research time within the operational budget for supportive care staff.

4.2.8 Select individual project initiatives to pursue that have a high potential and build teamwork

The very nature of supportive care necessitates consideration of a wide range of topics and issues. Given the underfunding for this component of the cancer care system, there are currently many gaps in service availability across Ontario. Heavy clinical workloads preclude many supportive care practitioners from active involvement in continuing education and community development activities. Supportive care networks are facing large challenges if they are to effect change in supportive care outcomes for patients and family members.

Additionally, as agencies providing supportive care begin to work together within regional supportive care networks, there is a need to establish rapport and build trust with one another. Historically, these agencies have not had the opportunity to engage in collaborative planning. Strategies need to be implemented to build a strong sense of teamwork between and among the supportive care members.

In light of these realities, supportive care network members need to create an agenda for action. It is suggested they identify projects, at the onset of their activities, that will help build skills in teamwork and have a good potential for success. A successful outcome will help members to see the value of working collaboratively and help to identify strategies for achieving effective collaboration.

4.2.9 Share information inventories among partner organizations about the availability of supportive care resources in regions

To have coordinated delivery of care, the ability to access relevant and needed information about supportive care services, including palliative care services, is critical for patients and family members as well as supportive care providers. Without knowledge of existing resources, it is difficult for providers to make appropriate referrals in a timely manner. Information about existing supportive care resources (institutional and community-based programs), including eligibility criteria and contact information, must be readily available to cancer care providers, including family physicians. Once service inventories regarding supportive care are collated, they need to be shared with partner organizations. Ideally, the inventory information ought to be available electronically to providers in their respective clinical settings, whether institutional or community based.

4.2.10 Promote the notion of family-centred approaches to supportive care

When cancer strikes, it has an impact upon both the individual with the disease and his or her family. Each family member must cope with the situation and may require help. Family members are also a critical part of a patient's support system. Many cancer patients describe family members and friends as playing significant roles in supporting them and assisting them to cope during the illness. To fulfill this role effectively, family members may need access to supportive care.

As programs of supportive care are designed and implemented, it is important to consider family-centred care. Patients may be treated for their cancer in the hospital or out-patient settings, but they live with their disease at home. Increasingly, with shortened hospital stays, family members are required to assume a large amount of responsibility for patient care at home. Accordingly they too need access to information, effective communication and support.

4.2.11 Give particular attention to palliative care

Comprehensive care for those who are experiencing life-threatening illness, especially those with advanced disease, is insufficient. Attention must be given to the needs of patients with cancer for pain and symptom control as well as other critical aspects of patient and family care, including home support, hospice care and bereavement counselling.

4.3 To improve access of individuals to the cancer system, to expedite movement of patients through the system, and to ensure quality of services available to patients

For patients with cancer and their caregivers, accessing and navigating the cancer system has become a complex and sometimes bewildering problem. The usual entry into the system is through a family physician or screening program. Either path would result in some preliminary investigation by the family physician and then most often referral to a surgeon for a tissue diagnosis, which usually involves a therapeutic surgical procedure as well.

At the point at which a pathologic/tissue diagnosis is established, staging investigations (laboratory, including special pathology techniques, and imaging) are required to determine the precise type and extent of the tumour. The next step is frequently referral to and consultation with radiation and/or medical oncologists regarding the desirability of using radiation therapy and/or systemic therapy (chemotherapy). A prolonged period of treatment with one or both of these modalities might be instituted. Next, the patient is followed with regular visits to physicians and investigations to detect any recurrent disease. If a recurrence is detected then any one or all of the treatment modalities (surgery, radiation, systemic treatment) might be required again.

Throughout this entire process, access to a whole variety of supportive care services (e.g. psychology, social work, nutrition) is an essential component of care. Some patients will need palliative care, and bereavement counselling for family and friends may be required. Continued contact with the patient's family physician of course should be maintained. This understandably confusing series of events can cause major difficulties for patients and, at times, for caregivers, including primary care physicians.

In order to facilitate entry to and navigation through this system, the current practice needs to be re-evaluated and specific strategies developed. In addition, measures must be taken to ensure the availability of adequate physical and human resources to provide timely care of high quality in an equitable fashion throughout the province.

Initiatives required to improve access of individuals to the cancer system, to expedite movement of patients through the system, and to ensure quality of services available to patients:

4.3.1 Secure adequate resources to ensure timely access of patients with cancer to appropriate care

As outlined above, the path a patient must take through the cancer system may involve many steps. These steps may involve a number of different institutions and providers; timely access to quality care requires adequate resources at each step for each provider.

Physical resource needs include facilities, imaging and laboratory equipment and supplies, radiation machinery, surgical operating rooms, equipment, drugs, etc. On the human side, required resources include physicians, nurses and technicians, specializing in areas such as

pathology, imaging, surgery, anesthesia and palliative care, in addition to oncology. Other professions play key roles at various stages as well, including public health physicians and nurses, pharmacists, dieticians, health educators, physiotherapists, social workers, psychologists, counsellors, community nurses, family practitioners and so on. The services provided by many dedicated volunteers are also essential elements in the ability to provide timely access to appropriate care.

For resources to remain adequate to meet needs, there must also be flexibility in how they are deployed. New and changing knowledge, technology, demographic patterns and disease trends cause shifts in how cancer control services are delivered and how many resources are required. Rapidly emerging knowledge about cancer genetics has the potential to dramatically alter how cancer prevention and care is delivered, thereby requiring significant shifts in the kinds and quantities of resources required.

Insufficient resources lead to crises in access to care. Potential crises loom on the horizon in areas such as systemic therapy, surgery, diagnostics and palliative care, again, just as in the current crisis in radiation treatment, due to critical shortages in trained professionals. The vast majority of the resources that contribute to cancer control in Ontario reside outside the legal entity known as Cancer Care Ontario; therefore, CCO's effectiveness in securing adequate resources for the cancer control system is based on the extent to which it can collaborate with stakeholders in gathering data, analyzing it, forecasting trends, planning on a system-wide basis, and advocating for resources and constructive change on behalf of patients, the public and the cancer control system. Examples of efforts to date include task forces mandated to examine and make recommendations regarding delivery of radiation and systemic therapy.

Much more extensive work is needed and will be built upon CCO's ability to develop its core competencies (described in section 3) and to engage stakeholders, primarily through the CCO regional (CCOR) councils and networks, in collaborating in this endeavour.

4.3.2 Ensure the successful planning, development and timely opening of new cancer centres

Three new regional cancer centres are to be opened in Durham, Peel and Waterloo regions in the year 2002. Additionally, a satellite radiation treatment facility in Sault Ste. Marie is in the planning stage, and Ministry of Health and Long-Term Care approval to develop a regional cancer centre in Niagara Region is expected. These new facilities are being developed to improve access to treatment for patients by increasing the capacity of the system to deal with the growing incidence of cancer, and by enabling services to be delivered closer to home. While these developments will expand the physical resources available for treatment, careful planning and implementation is required to ensure that:

- Adequate human resources are in place within the centres;
- Related services from other providers (e.g. laboratory, imaging, surgery and supportive care services) are also resourced to meet the accompanying shifts in volume.

4.3.3 Develop care paths for all common cancers

Caregivers, in consultation with a patient, must develop an individual care plan for each patient. A care *path* is an algorithm that can provide guidance in determining the care *plan*. These paths should include an outline of what is expected at each step throughout a patient's illness and how a patient should proceed from one step to the next. In addition to the care path being a directional guide, some goals with regard to time intervals between each step should be included. These paths should be constructed in such a way that they are helpful to caregivers at all levels, and are available in a format that is understandable to patients and the general public. They can also be used to monitor the clinical course of patients to ensure that interventions are applied appropriately in a manner that is consistent with the best evidence.

Given the unique needs of each cancer patient, and given that the organization of services is unique to each region and institution, CCO will develop generic algorithms for all the common cancers. These can then be used as skeleton frameworks to enable providers to create care paths that are relevant to specific regional and institutional settings, and to develop with patients individual plans for their care.

4.3.4 Provide designated case managers/navigators to those patients who require such assistance

It is neither practical nor necessary to assign all of the approximately 50,000 new Ontario patients with cancer each year to a dedicated case manager over and above current caregivers. In many instances, the role will be carried out by the family physician or by the local Community Care Access Centre. In some cases, primary care nurses, either in general hospitals or cancer centres, will fill the role. Certain groups of patients, however, would benefit from designated case managers/navigators. Although some guidelines should be developed provincially, the type of patient who requires such assistance and the job description of case managers would best be determined on a regional basis, with care taken to avoid duplicating existing services.

4.3.5 Further integrate family physicians into cancer care programs

Section 3.2.5 spoke to the need to support the essential role of the family physician in the management of cancer care. To further the goal of improving access to services by patients with cancer, the following steps are recommended:

- Establish a provincial network of family physician leaders to define and promote the role of family physicians in the care of patients with cancer. This should specifically include enhanced roles in the treatment and follow-up phases of care.
- Improve communication links between family physicians and specialists in cancer care.
- Develop information products for family physicians that will provide them with disease-specific cancer information including prevention, screening and early detection, treatment and follow-up guidelines. This will require the development of a system of delivering this information to make it most accessible to family physicians.
- Develop appropriate cancer education programs for family physicians using methods that have been shown to be effective. These programs should be developed with the involvement

of family physicians and the organizations that support them, such as the Ontario College of Family Physicians and the Ontario Medical Association.
- Support and promote the activities of a newly appointed provincial coordinator of the family practice initiative.

4.3.6 Promote the involvement of community surgeons in the cancer system

Section 3.2.5 also identified the essential role of surgeons in providing cancer care. Surgical oncologists across Ontario have been linked to the Surgical Oncology Network (SON) under the guidance of a program coordinator associated with CCO. The next phase of the SON's work is to begin linking with community surgeons who perform cancer surgery.

The SON's main goals are to enhance communication and decision making within the surgical community, and to engage in research and educational activities relevant to surgical practice. The essential questions faced by surgeons and their patients are:

- Is surgery needed?
- If yes, can it be done in the community (i.e. high-volume, low complexity cases such as breast and colorectal cancers) or should it be referred to a surgical oncologist specialized in the particular disease site because of the complexity of the case?
- Should the patient be referred for any other consultations or treatments prior to or after the surgery?

As a first step in addressing these questions, the SON has created a database of experts in surgical oncology by disease site (e.g. head and neck, gynecologic, genitourinary) who are part of a multidisciplinary team in the cancer centre. The next step is to use the Internet to make this database accessible, with appropriate password protection, to community surgeons. The critical step will be to encourage community surgeons to identify the subspecialists (via the database) with whom they can consult if necessary to help the surgeon–patient pair through the decisions needed in some situations. To this end the SON will undertake a number of initiatives, such as expanding its Web site content, creating e-mail discussion lists, promoting regional workshops, and conducting a needs assessment and satisfaction survey. Clinical guidelines will be developed with input from surgeons along with outcome studies to assess the benefits of the program in maximizing patient care.

The next phase in network development will be to provide family physicians and patients with information to enable them to seek the best advice from the practicing surgeon in the community as a continuing effort to ensure quality care as close to home as possible.

4.3.7 Continue to promote and develop CCO regional networks in systemic therapy, radiation therapy, supportive care and diagnostics

The regional networks have demonstrated the ability to provide a forum for education and problem solving across institutional boundaries. While the basic structures for these networks have been put into place, continuing attention to promoting, developing and nurturing these networks is needed to reap the full benefits for the cancer system.

4.3.8 Improve the speed and ease of investigation and care of patients found to have abnormalities by providing assessment centres for specific disease sites

Once an abnormality is detected by a family physician or through a screening program, an assessment centre for a disease site would offer the potential to act as an express lane for biopsy, surgery and staging. Close liaison and integration with diagnostic services such as pathology, laboratory and imaging are required.

4.3.9 Ensure that supportive care services are available at each step of a patient's journey through the cancer care system

More specific steps to complete this initiative are described in section 4.2.

4.3.10 Expand the New Drug Funding Program to a comprehensive managed anticancer drug program

There is need for a more comprehensive program that includes oral drugs (currently funded for eligible patients through the Ontario Drug Benefit or Trillium programs) and some old but expensive agents.

4.3.11 Ensure quality care in all regions of Ontario

This initiative will require:

- Continued and expanded support of the evidence-based care program (see section 4.2);
- Continued development of standards for delivery of care;
- Development and implementation of appropriate quality indicators as part of an integrated provincial quality management program that will allow proper monitoring of cancer care across the province;
- Development of an information system that provides timely and accurate data on all patients, their disease and treatment (see section 3.3);
- Development of a process for collecting and reporting waiting times for all aspects of cancer care including surgery, imaging/radiology and pathology reports;
- Effective planning and appropriate resources (see section 4.6);
- Recognition that, at a time when so much cancer care depends upon advanced radiation and surgical technology, new complicated drug regimens, and sophisticated electronic

communication systems, in the final analysis quality care depends upon one-to-one interactions between an individual patient and a health professional (see section 3.1).

4.4 To improve the knowledge of the public and professionals as to the causes, indicators and treatments of cancer

Improving the knowledge of the public and professionals as to the causes, indicators and treatments of cancer should result in people making better decisions about their health and care. It is also important to understand the structure of the cancer system and find answers to questions such as: Where can patients access service? Whom should patients approach? What services are available? By having ready access to these types of information patients should receive the most appropriate care in the most appropriate location, resulting in improved outcomes and increased satisfaction.

The challenge in improving knowledge includes the following:

- Information must be credible and reliable (and seen to be so by the public and professionals alike).
- Information must be readily available and understandable when and where users need it to help them understand choices and make decisions.
- Information must be delivered in such a way that it enhances the potential to influence decisions and behaviour of professionals and the public and leads to improved health.

Useful information on cancer is already available from many credible and reliable sources such as the Cancer Information Service, the Canadian Cancer Society, public health units and other providers of cancer control services. At the same time, there is an explosion of information available on the Internet—a search for Web pages on the topic of cancer results in millions of "hits". There remain significant deficiencies in:

- Information needed versus what is available;
- The quality and reliability of information;
- The ease with which information can be accessed when and where it is needed or is likely to have the greatest impact;
- Understandability and accessibility for the public in general, and especially for marginalized populations.

Initiatives required to improve the knowledge of the public and professionals as to the causes, indicators and treatments of cancer:

4.4.1 Provide a forum to enable partners to collaborate in developing a strategy to ensure that the information needs of the well public, patients, and community health professionals in Ontario are met through appropriate communications methods and from credible, accurate sources

Through the mechanisms of its provincial and regional-level education committees, CCO is well placed in Ontario's cancer control system to collaborate with many partners to ensure that

information gaps are identified and filled by the most appropriate source(s). Its ability to act as a catalyst for improving knowledge is directly related to its capacity to generate, gather, synthesize, use and disseminate knowledge about cancer, its capacity to communicate clearly and respond sensitively, and its capacity to collaborate with partners. The means for further development and maintenance of these capacities is discussed in section 3.

Given CCO's mandate to integrate and coordinate the province's cancer services, it has an obligation to ensure that the overall knowledge needs of the public and professionals are met by the many contributors in Ontario's cancer control system, and that the information provided is consistent with the most up-to-date knowledge available. With its commitment to evidence and evaluation, CCO also must ensure that the development of information and communication strategies is linked to identified, desired, measurable outcomes, such as satisfaction with the quality of information, impact on practice patterns, or survival.

4.4.2 Continue to take a leadership role in improving knowledge and influencing practice behaviour of physicians and other health care professionals

CCO has traditionally played a key role in the training and continuing education of health care providers who provide cancer treatments. A new initiative in this area is described in section 4.2.2.1 (the development of clinical information systems to influence practice at the clinical encounter).

With its expanded mandate, CCO also has an obligation to ensure that community-based health care providers are enabled to improve their knowledge and practice behaviour. Specific initiatives regarding community surgeons, family physicians and supportive care providers are described in sections 4.2 and 4.3. CCO has completed an extensive literature review on effective educational strategies for reaching and influencing the clinical practices of community-based health care providers and is committed to initiating pilot studies in this area. Furthermore, CCO will undertake development of Internet-based tools to enable ready access by community-based providers to databases (e.g. clinical trials) and other information.

4.4.3 Develop tools to facilitate access to information by the public and patients

The cancer control system in Ontario is fortunate to have numerous providers who are developing and producing information on cancer. CCO is committed to developing information tools to facilitate patient and public access to these many sources of information. As presented in section 4.2.2.2, CCO will develop tools for access to electronic information by patients, such as offering Internet access in the clinic. Through further development of its Internet site, and in close collaboration with the Cancer Information Service, CCO will provide links to credible and reliable sources of information, provide access to useful databases (such as its inventory of education materials), and work with partners to create new content.

4.4.4 Initiate pilot studies on effective education strategies for marginalized populations

There are identifiable groups within the general population that are known to experience higher cancer mortality and morbidity and to be underserved with respect to cancer programs. Three

such subpopulations are: individuals with low literacy, individuals with limited financial and social resources, and individuals from non-dominant cultures, particularly those who cannot communicate fluently in English or French. CCO has completed a literature review on effective communications strategies to reach such groups, and is committed to initiating pilot studies to achieve specific cancer education goals.

4.4.5 Develop a resource guide to Ontario's cancer system

Cancer Care Ontario needs to develop a comprehensive resource guide that would provide referring physicians, patients, the public and the media with easy access to the province's cancer care providers, by including information about where to find cancer specialists in their regions and across the province. The guide would be primarily an electronic publication but print copies would be required for initial promotion and for individuals who do not have Internet access.

4.5 To advance knowledge about cancer control through research

Continued improvement in cancer control involves the complete spectrum of cancer research, from studies of tumour biology, through clinical trials and outcomes research, to evidence-based care and health services research. The activity of cancer research is essential for retention and recruitment of the most highly qualified and competent health professionals needed in the province. To achieve this goal, mechanisms must be found to allow health professionals the opportunity to exercise their investigative capabilities. At present, explicit support and protected time for research is limited to a relatively small number of career and clinician scientists.

The creation of CCO provides unprecedented opportunity for research into strategies for cancer prevention, development of evidence-based guidelines for systemic, surgical, radiation and supportive care and the economics of cancer control, as well as the more traditional areas of fundamental and clinical research. It also provides an organizational architecture capable of supporting and fostering transfer of knowledge through the continuum of laboratory, clinical and population research. To access these opportunities effectively, it will be important to establish a broad vision of CCO's research mandate in collaboration with funding agencies and CCO's affiliates, many of which are substantially involved in various aspects of cancer research. It will also require identification of additional funding sources and partners.

Since conception of the original strategic plan, the health research environment has undergone, and continues to undergo, major change. The proposed creation of the Canadian Institutes for Health Research offers both opportunities and challenges. To take maximum advantage of new funding opportunities, it is essential that CCO demonstrate a strong commitment to supporting the full spectrum of cancer research.

Initiatives required to advance knowledge about cancer control through research:

4.5.1 Access and develop the research capabilities of health professionals

CCO has the potential to become the paradigm for cancer control agencies worldwide. Meeting this potential will require acceptance of the need to provide protected time for all appropriately

qualified and capable health professionals wishing to contribute to the cancer research effort. While the provision of protected time has significant budgetary implications, the enhanced ability to improve efficiency through advances in information science and health service systems will provide opportunities to offset these costs.

CCO should:

- Build protected time for research into the operating budget by incremental funding, perhaps in an alternative payment plan for oncologists;
- Secure funding for outcomes and health services research;
- Improve support for psychosocial and supportive care research.

4.5.2 Enhance translational research activity

Researchers capable of bridging the interface between laboratory and clinic, or between the clinic and population are rare. It is this transitional interface that presents a major obstacle to transferring the results of fundamental and clinical research into accepted clinical practice. As the growth in knowledge about cancer explodes, particularly in regard to the human genome, CCO needs to identify additional funds to recruit research personnel qualified to expedite this translational process and to invest in identification and training of the next generation of such investigators. To achieve this objective, CCO should:

- Establish a program to support the training and recruitment of investigators working at the interfaces of fundamental, clinical and population research;
- Identify new funding partners such as the Canadian Institutes for Health Research, industry and other corporate sponsors;
- Promote and strengthen participation in clinical trials.

4.5.3 Identify and secure funding for research priorities

The last decade has witnessed unprecedented advances in understanding of the molecular causes of cancer and the ability to rapidly design, synthesize and screen potential anticancer drugs. Similarly, sophistication of instrumentation for diagnostic imaging and for extracting molecular, prognostic information from early stage tumours has advanced at a comparable rate. Ontario researchers have made important basic and clinical contributions to all of these areas. However, the ability to keep pace with technological change has been compromised by lack of funds and Ontario now lags behind in a number of key areas, such as early detection, experimental therapeutics and molecular diagnostics. The creation of the Ontario Cancer Genetics Network, through research funding from CCO, has provided an excellent example of a research initiative in molecular diagnostics that has rapidly evolved to become a significant service resource. For CCO to continue to ensure timely access to the benefits of advances in these areas of cancer research will require strong basic and clinical research programs, supported by a significantly increased budget.

CCO should:

- Secure stable, adequate funding for the Ontario Cancer Genetics Network;
- Support targeted initiatives in imaging research, molecular diagnostics, experimental therapeutics and occupational and environmental carcinogenesis;
- Strengthen clinical trials infrastructure to support increased involvement in phase I and phase II trials.

4.5.4 Recognize and respond to major changes in the funding of health science research

Major changes are occurring in the funding of health science research. Provincial and federal programs such as the Ontario Research and Development Challenge Fund and the Canadian Foundation for Innovation have provided opportunities for partnerships among government, publicly supported not-for-profit agencies and industry in all areas of science and technology. The creation of a new federal agency, the Canadian Institutes of Health Research, to replace the Medical Research Council, is in progress. The final structure of the CIHR will have major implications for the funding of cancer research and the relationship among a CIHR Institute of Cancer Research, provincial cancer agencies and the Canadian Cancer Society-supported National Cancer Institute of Canada. Whatever the final structure, CIHR should provide increased funding for the complete spectrum of cancer research, as well as opportunities for the provincial agencies to partner in targeted research initiatives, and recruitment and support of research personnel. For CCO to take advantage of these matching opportunities will require identification of additional research funds and new funding partners. Now is an opportune time to revisit the research vision of CCO and to secure for the organization a role in the rapidly changing research environment in Canada. CCO should:

- Be proactive in partnering with industry;
- Secure additional funds from government;
- Establish consortia of research groups to access funds through CIHR;
- Explore partnerships with other provincial cancer agencies and hospital research institutes;
- Partner with the MOHLTC, Health Services Research Network and CIHR to ensure continued and increased funding for health services research;
- Hold a research retreat in broad consultation with representatives of other cancer research constituencies to revisit the vision of CCO's strategic role in cancer research;
- Define CCO's role with respect to other agencies in the overall funding of cancer research in the province.

4.5.5 Enhance the visibility and recognition of existing CCO-supported research

The research profile of CCO must be raised if it is to become the leading knowledge broker in the province on issues of cancer control. It is a widely accepted premise that the quality of research carried out by health organizations and institutions is an indicator of the quality of care they deliver. CCO's current contribution to cancer research in the province is substantially undervalued, creating the potential of unjustifiably undermining the confidence of patients in the care they are receiving.

To some extent, the lack of visibility of CCO-sponsored research is attributable to the success with which CCO has integrated its research efforts with universities, research institutes and various other academic and health care institutions throughout the province. Overall, this integration has been extremely successful in providing critical mass and stability, particularly to research groups associated with the regional cancer centres. It has also been very effective in leveraging CCO's limited research resources and nothing should be done to jeopardize the strong relationships that have developed over the last decade. However, success in research has more often than not been promoted by, and attributed to, partner institutions and peer-reviewed funding agencies, while the involvement of CCO has been lost. To redress this problem, CCO should develop a corporate research identity by:

- Establishing central and interlinked research sites on the Internet;
- Increasing use of other advertising and communications media to profile research;
- Increasing communication between existing research groups via workshops and video conferencing;
- Establishing formal research agreements with current and future partners.

4.5.6 Become knowledgeable about, and advocate for, all cancer research in Ontario, including that done outside of the CCO centres

Because CCO's domain now is the entire cancer system in this province, it should begin to take a role in research done outside the CCO centres. This role should be to collate information about cancer research in the province and to advocate for all Ontario cancer researchers.

4.6 To ensure the effective planning, organization, management and delivery of cancer control services

For cancer control services to be planned, organized and managed effectively, initiatives are required to enable the many stakeholders to share and analyze data, to forecast and identify issues, to agree on solutions and to develop and implement plans. Above all, the structure and tools for planning must heighten the system's ability to respond promptly to new knowledge about cancer and its treatment; this is especially critical given the potential revolution in cancer care that is about to occur with the complete sequencing of the human genome. Pursuit of these initiatives is dependent upon CCO developing strong capabilities in each of the core competencies discussed in section 3, i.e. the capacity to:

- Respond sensitively to the continuum of needs of people with cancer or at risk of being affected by cancer, and to communicate clearly and knowledgeably to all stakeholders;
- Collaborate with existing and prospective partners;
- Generate, gather, synthesize, use and disseminate knowledge about cancer;
- Obtain, retain and manage appropriate resources (human, operating and capital).

Initiatives required to ensure the effective planning, organization, management and delivery of cancer control services:

4.6.1 Continue to evolve appropriate organizational relationships and structures to enable numerous organizations and individuals to plan and organize collaboratively

Section 3.2 described initiatives to develop CCO's capacity to collaborate with partners; more specifically, section 3.2.4 spoke to the need to facilitate the ongoing evolution of CCO regional councils and region-specific organizational structures that link communities, networks, providers and CCOR councils. As articulated in section 3.1.1, CCO is committed to its policy of involving people whose lives have been touched by cancer to participate in the decision-making structures. This is a critical requirement to ensure plans are responsive and sensitive to the needs of people with cancer or at risk of being affected by cancer.

One regional structure that has proven to be very beneficial to patient care and should therefore be pursued in other regions is described below.

4.6.1.1 Extend the comprehensive cancer centre partnership arrangement to additional regional cancer centres–host hospitals

Comprehensive cancer centres are formed through partnerships that bring together as a single entity the ambulatory programs in a regional cancer centre and the in-patient cancer programs of its host hospital. This form of partnership agreement was pioneered at the Toronto-Sunnybrook Regional Cancer Centre, and has been adopted for the new Grand River Regional Cancer Centre. It enables more integrated planning and seamless care within the centre/hospital setting, and serves as a base for greater integration of services across a region.

4.6.2 Extend the capability to collect, share, analyze and evaluate data across the cancer control system

Section 3.3 described the initiatives required for CCO to develop its capacity to generate, gather, synthesize, use and disseminate knowledge about cancer. The initiatives included the need to:

- Safeguard privacy and the confidentiality of personal information;
- Define and implement standard data sets;
- Source and implement clinical information systems;
- Develop data warehouse technology;
- Strengthen capacity for data analysis and evaluation.

While CCO must develop its own capacity in these areas, it must work with partners to enable these capabilities to be extended across regions.

4.6.2.1 Begin to build information technology infrastructure starting with pilot studies of information system linkages among RCCs, host hospitals and community oncology centres

Regional information system linkages among RCCs, host hospitals and community oncology centres are necessary first steps in an incremental plan to achieve region-wide information systems. These data might include information on, for example, waiting times for cancer surgery,

average length of stay for common cancers following surgery, compliance with provincial practice guidelines or the nursing time provided for in-home care of cancer patients by CCACs. Such information would greatly assist decision makers in developing strategies that would use resources more efficiently and realign system components.

Another important step will be the purchase or development of a specialist module for the management of patients requiring chemotherapy that can be used by medical oncologists in the community regardless of the electronic patient record used in their office and hospital (see section 3.3.3). Until now, OPIS 2000 has required that the user also have in place OPIS, the CCO information system module to track selected aspects of oncology patient information. The use in the community of a standalone OPIS 2000 system or other similar commercial software would enable the capture of data that would increase understanding of the scope and level of systemic therapy activity outside of the formal system.

4.6.2.2 Advocate with partners to remove legislative and policy barriers to sharing of essential data

Existing initiatives, such as the province-wide cervical screening database (Cytobase), are being held back due to legislative or policy barriers to sharing information. Both the federal and provincial governments have drafted legislation affecting personal health information; CCO must continue to monitor these developments and, with its partners, advocate for access to the data required to inform an effective cancer control system.

4.6.3 Extend the capability for system-wide planning across cancer control partners

Section 3.4 outlined initiatives CCO must undertake to develop its capacity to obtain, retain and manage appropriate resources. While CCO must develop its capabilities to analyze, forecast and plan for its own operations, its role as principal adviser on cancer issues to the Ministry of Health and Long-Term Care requires it to provide leadership in bringing together partners to collaborate on system-wide plans.

4.6.3.1 Develop standardized templates for the development of regional operating plans

It is clear from the recent radiation therapy crisis that system-wide operating plans with one-, three- and five-year horizons are essential to avoiding future crises. Planning must also enable flexibility to adapt to unforeseen changes in the environment.

To enable development of an accurate provincial operating plan for cancer services, it is essential that standardized regional templates be developed into which data with common definitions can be inserted. The roll up of regional operating plans into a single provincial operating plan must be undertaken in a transparent fashion that ensures that the region's prioritized needs are addressed. Workload measurement and staffing standards would enable greater consistency.

4.6.3.2 Implement human resource planning and development programs

The cancer control system faces serious problems in delivering services due to severe human resource shortages at many different points in the cancer control continuum. Not only are there shortages of professionals needed for radiation treatment and systemic therapy, patients also face delays in accessing diagnostics, because of shortages of laboratory and imaging personnel; surgery, because of shortages of anesthetists and general surgeons; and supportive care, because of shortages of community nurses and palliative care professionals. The population demographics clearly indicate that the burden of cancer care will increase dramatically over the next decade. Therefore, planning for human resource needs across organizations and stages of service delivery is urgently required.

4.6.3.3 Re-examine models of care delivery and develop staffing standards for health care professionals

In collaboration with stakeholders, CCO must take the lead in developing provincial staffing standards for all health professionals involved in cancer service delivery. It must also look critically at the roles of health care professionals to identify ways of doing work differently within and between disciplines. Research into different methods of health care delivery is to be encouraged. CCO will encourage partners to join together in advocating for alterations to funding mechanisms to support improvements in delivery of care.

4.6.4 Use cost data to guide realignment of the cancer care system

Hospitalization is the principal cost driver of the cancer system. Approaches that reduce the inappropriate use of acute care beds may provide qualitatively better choices for patients at less cost to the health system. Region-specific data on the average length of stay for the surgical management of common cancers and for the terminal care of patients can be used to guide practice changes such as greater use of day surgery for breast cancer surgery, the development of ambulatory diagnostic units, and the provision of home-based supportive care for the terminally ill.

Information on the cost of cancer control activities across organizational boundaries can be used to assist decision makers in these organizations to realign the system, to identify efficiencies, to accurately predict the fiscal impact of the introduction of new prevention, treatment and supportive care programs and to determine the cost-effectiveness of new approaches. A CCO Cost Information Network is in its formative stage requiring the establishment of an advisory committee to prioritize its activities and infrastructure support to enable it to begin to capture and analyze cost data.

4.6.5 Work with partners to seek solutions to resource problems

Section 3.4.4 identified the need for CCO to secure appropriate levels of and mechanisms for funding. Together with the development of system-wide plans for cancer control, CCO is

committed to working with its partners to find solutions to resource problems, and when necessary, to advocate strongly for changes to funding mechanisms and/or increased resources.

Resource problems are not limited to those caused by too few dollars. The current crisis across the health care system in Ontario is the result of too few trained professionals to meet all the service needs. Two initiatives to address this specific resource problem follow.

4.6.5.1 Promote careers in oncology and play a role in defining the health professional training programs necessary to meet current and future needs

The ever expanding requirement for expertise in cancer care means that young people need to be stimulated to consider cancer care as a profession whether in radiation therapy, nursing, pharmacy, medical physics or medicine. Short-term fellowship programs and/or electives are established methods of attracting young people into oncologic specialties. CCO needs to work with Ontario's universities to ensure that this objective is achieved. CCO must ensure that once appropriate workload standards are established for radiation and medical oncologists, the training programs are sized to meet current and future needs.

CCO staff should play a major role in undergraduate and continuing education of health professionals involved in care of patients with cancer. These programs should not only address the technical aspects of patient care but must also stress the importance of the sensitive delivery of patient-centred care using the best methods of patient–health care professional communication. (See section 3.1.)

4.6.5.2 Advocate for funding mechanisms and levels to enable effective recruitment and retention strategies and ensure high quality of work life

It is recognized that all health care professionals working within the cancer system are feeling the impact of years of fiscal constraint and an increasing case load burden. Not surprisingly, there is a palpable decline in the morale of health care professionals within the provincial cancer care system. CCO must take the lead to ensure that compensation is competitive within Canada and that the quality of work life is such as to ensure retention within the provincial system. Funding to explicitly protect time for research and education activities outside of clinical activities would be an important step toward improving quality of work life.

5 IMPLEMENTATION

Assuming approval of this strategic plan by the Minister of Health, Cancer Care Ontario will proceed to develop an implementation plan within the resources provided for its operating plan. Pursuant to its Memorandum of Understanding with the Ministry of Health and Long-Term Care, CCO also will proceed to work with its partners in developing a three-year business plan for the cancer control system.

6 APPENDIX

6.1 Current environment: external and internal

Having started its existence as The Ontario Cancer Treatment and Research Foundation (OCTRF), the organization was reborn in April 1997 with an expanded mandate from government and a new name. Cancer Care Ontario immediately began to build a strategic plan to guide its early development. Approved by its board of directors in October 1997, the first strategic plan set out strategic goals to March 2000. To continue the planning into the future, CCO prepared the following assessment of its external and internal operating environments to guide development of this strategic plan.

6.1.1 Fiscal milieu

The fiscal climate at both the federal and provincial levels shifted noticeably in the first quarter of 1999, as reinvestment in health care became the priority. New funds flowed in the lead-up to the June 1999 Ontario election, but it is unclear how long this change in fiscal climate will be sustained.

6.1.2 Health care delivery system

Reform of the health care system can be expected to continue at both the federal and provincial levels, but the rate at which it will take place is uncertain. At the provincial level, the Ministry of Health and Long-Term Care has appointed regional directors and is continuing with its implementation of regional offices. In discussions between the Ministry of Health and Long-Term Care and the Ontario Health Providers' Alliance (of which CCO is a member), the ministry appears committed to completing hospital restructuring and primary care reform, and to the Smart System for patient health information. At the same time, momentum seems to be growing for more funding and greater integration of the home care sector.

6.1.3 The cancer control system

In fulfilment of its mandate, CCO has made fundamental changes in the way it works with the Ministry of Health and Long-Term Care. The MOHLTC appears to have acknowledged that the cancer control system is different from other aspects of the health care system as evidenced by the appointment of a Senior Policy Adviser on Cancer Services. The MOHLTC's acceptance of the Task Force on Human Resources for Radiation Services cost-per-case funding formula for radiation treatment is a landmark development that, for the first time, gives CCO the assurance that its funding will grow as patient numbers grow. The ministry's acceptance of the concept of dealing with volume issues through increased compensation for increased workload is groundbreaking.

CCO has made fundamental changes in how it operates within the cancer control system. CCOR councils have been launched and have begun the process of data sharing and problem resolution

among the many partners within each region. CCOR councils are now poised to begin to play their primary role in planning and coordination of the cancer system.

Pressures to improve the cancer control system continue and include the following:

- The Minister's announcement that the goal of treating radiation patients no more than four weeks from referral will be achieved in Ontario;
- The impending development of a national cancer strategy by the Canadian Association of Provincial Cancer Agencies in collaboration with the National Cancer Institute/Canadian Cancer Society and Health Canada.

6.1.4 The research frontier

The federal government's announcement of plans to create the Canadian Institutes for Health Research should have a positive influence on the quantity and quality of research that will shape the future of health care and cancer control. Specific developments likely to have an impact in the foreseeable future include the impending sequencing of the human genome, the use of systemic agents for primary cancer prevention, the efficacy of and broadening indications for numerous new systemic treatments, and dramatic improvements in imaging and molecular diagnostic techniques. Research developments will continue to prompt fiscal pressures, as the costs of new drugs and diagnostic/treatment technologies will likely be much higher than those that they will replace. At the same time, the growing body of research in information science and health service systems has the potential to identify and realize efficiencies to mitigate the fiscal pressures.

6.1.5 The increasingly informed and questioning public

The amount of information available on health and health care has multiplied exponentially, and access to it has become much cheaper and easier. There has been extensive coverage of these topics in the traditional print and electronic media and, in addition, the Internet continues to grow as a dominant mode of communication.

As a result, public expectations continue to rise in terms of choice and access to new treatments. Concurrently, the public demands more accountability from its institutions in the form of performance reports. The proliferation of information raises the challenge of dealing with the quality of information used by patients and society at large to make decisions.

On the other hand, communication with all segments of the public remains challenging. The knowledge gap is growing between the informed public and the more marginalized groups (e.g. low literacy, low income, remote location). The means to reach these groups are complex, but are essential in the pursuit of CCO's goals.

6.1.6 CCO programs and resources

Over the past two years, CCO has been very successful in attracting additional funding for new or expanded programs. Total operating funding from the Ministry of Health and Long-Term Care

increased from $154.6-million to $188.4-million, and approximately $193-million in projects to expand existing centres and construct new ones have received ministry approval. Funding for research from a variety of external sources has grown by about 30%. Furthermore, the mode of funding for the radiation program has recently changed to the per case method, thereby enabling funding levels to adjust in relation to the demand for radiation treatment.

The additional operating funding has enabled an Aboriginal cancer care program and a province-wide cervical screening program to be put into place. Funding for some genetic screening and counselling services is allowing implementation of some of the research findings of the Ontario Cancer Genetics Network. Notable program expansions include the growth of the New Drug Funding Program (annualized budget increase from $5-million to $20.3-million), the Ontario Breast Screening Program (number of screens increased by 25%) and the Program in Evidence-based Care (guideline production capacity increased from four to 15 per year).

While CCO has received increased funding, it remains constrained in its flexibility to respond to needs, since the ministry requires specific dollars to go to specific programs. Resource limitations have proved problematic in a number of areas. Shortages of professionals required for radiation treatment have been well documented and similar problems are imminent for systemic treatment. The pressures are augmented by poor performance in attracting students to the oncology professions, and in retaining staff. CCO's research efforts are constrained by low levels of provincial funding and limited time available for research by professional staff beyond the few designated as clinician-scientists or research-scientists. Furthermore, management ranks have been stretched to cover the significant number of capital projects and, at the same time, to implement initiatives related to CCO's expanded role (e.g. reviews of access to, and resources for, systemic therapy and diagnostic services).

6.1.7 Information and information technology

CCO has recently completed an assessment of the information requirements to support its vision and goals. A phased and costed business case to meet these needs is being developed for presentation to the CCO board in the fall.

At present, access to the information needed to plan and/or manage the cancer control system is deficient. The information needs assessment noted the limited information available on activity outside the CCO regional cancer centres. Both the Canadian Council on Health Service Accreditation and the Office of the Provincial Auditor have noted that CCO does not yet have in place a system of indicators to measure the quality of its operations across the province. Similarly, the auditor reported that the Ontario Breast Screening Program lacks sufficient mechanisms to monitor whether screening centres meet performance standards, to ensure high risk women are identified for screening, and to follow up with radiologists who have missed cancers at the screen.

6.1.8 Relationships

In the two years since CCO's inception, the organization has embraced its broader role and put into place the basic structures for the operations of the eight regional entities known as CCORs.

CCOR councils are comprised of representatives from a variety of stakeholder agencies and groups in their respective regions. The primary function of the CCOR council is to review the status of cancer control services in the region and, based on this review, to develop policies and priorities for regional development and/or reinvestment in cancer control services, within guidelines established by the board of CCO. Through the CCOR, CCO enters into affiliation agreements with related agencies and groups, and encourages CCOR affiliates to participate in data collection and submission, and planning and coordination of cancer services within a provincially established framework.

At the provincial level, a forum has been established to bring together the advice of several province-wide stakeholder organizations. The President's Advisory Council includes representatives of the Canadian Cancer Society, Ontario Division, Princess Margaret Hospital, the Ontario Hospital Association, the Ontario Medical Association and the Registered Nurses Association of Ontario.

The most critical relationship for CCO is with the Ministry of Health and Long-Term Care, from which it receives its authority and the vast majority of its funds, and to which it is wholly accountable. A very constructive development in this relationship is the appointment of a Senior Policy Adviser on Cancer Services for the Ministry of Health and Long-Term Care. The adviser has greatly facilitated acceptance by the ministry of a Memorandum of Understanding between the two organizations.
Other key relationships for Cancer Care Ontario are with the eight hospitals that host existing regional cancer centres, and four additional hospitals that have cancer centres under development. These relationships received important support from the Minister of Health when she endorsed a CCO/host hospital partnership model.

Integration of activities between CCO and Princess Margaret Hospital, the only provider of radiation treatment outside of CCO and a key participant in cancer research and care, have been facilitated through the organization of CCO Central East Region. This venue has led to collaborations such as a joint plan for radiation treatment for the region.

Building trust with all its partners remains a challenge for CCO. Many affiliates and potential partners are exercising caution and are looking for the added value that will be obtained by working with CCO. Some hold concerns about CCO's intent, questioning whether CCO is seeking collaboration or control. To overcome this skepticism, CCO will need to prove itself to its partners.

6.1.9 CCO organizational culture

CCO employees continue to demonstrate a very strong commitment to the vision of reducing the burden of cancer in Ontario. They also exhibit a high level of knowledge and professionalism to fulfill their roles. Participation of cancer system partners and community representatives at the CCOR and provincial levels has been extensive, demonstrating that there is a willingness to work with CCO and offering legitimacy to the planning and policy-setting process. The organization is still evolving from its OCTRF days to embrace a regional structure and mindset. The management style and skills needed to shift from controlling resources within a regional

cancer centre to attracting and collaborating with partners across a region are still under development.

Although CCO researchers operate in an environment of enquiry and rigorous standards, this approach has not yet permeated through the entire organization. This type of culture is essential to maintaining and improving the quality of cancer control. Unfortunately, although CCO researchers continue to compete successfully for funding from both private and public sectors, CCO's overall research effectiveness, impact and visibility suffer as a result of limited interaction among its various research groups. High clinical volumes, lack of protected time, lack of incentives and a perception that the organization places less value on research than on clinical practice have combined to limit research by CCO professionals.

6.1.10 CCO leadership

CCO has been successful in demonstrating its ability to mobilize and deploy its intellectual capital to provide leadership for the cancer control system. Examples include the Task Force on Human Resources for Radiation Services, the Expert Panel on Colorectal Screening, the Task Force on Pancreatic Surgery and the Program in Evidence-based Care.

On a broader level, CCO has succeeded in raising its profile with politicians and the media over the last year. The April 1998 launch of *Ontario's Interim Cancer Report Card*, publications by CCO staff, and coordinated prompt replies to interview requests, have established and reinforced CCO's position as a credible resource among reporters and political staff for commentary on cancer issues. CCO's position on a number of contentious issues has been reported accurately. In the last few months, CCO has been very successful in receiving positive responses from government, including a substantial infusion of new funds.

CCO is fortunate that the subject of cancer control currently enjoys a high level of political and public currency, and the need remains strong for leadership and coordination of a fragmented delivery system. CCO remains well placed to build on its support and to solidify the legitimacy of its position.

On the other hand, CCO has yet to be fully accepted as the principal adviser on cancer control in the province. Recognition of its role in less formal terms (e.g. some aspects of the working relationship with Princess Margaret Hospital and with hospitals hosting new cancer centres) is also moving slowly. CCO needs to reconcile the perceived conflict in being the coordinator and principal adviser for the entire cancer system while being the manager of a part of that system.